

A Caregiver's Perspective

By

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Comments delivered by Katryna Gould at a Press Conference celebrating National Family Caregiver's Month with Assistant Secretary Josefin G. Carbonell at the National Press Club, Washington, DC, on November 18, 2004.

Good morning. I am grateful for the opportunity to speak to you today.

I became a caregiver in 1990. At that time, while evidence of the aging of our population and accompanying effects on our society was the subject of much study, the sandwich generation had not yet been named, and resources for the frail elderly and their families, while available, were not easily found.

Our family is very fortunate – we have lived in Washington, D. C. for forty years and have strong ties here. Of equal, if not greater importance, our doctor, a skilled diagnostician, and an observant, sensitive practitioner, manages to keep in touch with both services available to the frail elderly and their caregivers in our community, and with new thinking in how best to care for this growing part of our population. While these circumstances may not be typical in some respects, experiences that other caregivers have shared with me confirm that my own experiences, feelings, frustrations and triumphs are shared by many, and that the observations I make are raised by many voices.

I have cared for my husband's mother and both my parents. As is the case with many of us, I began my time as a caregiver without professional training or portfolio. After my husband and I were married, his mother, Katherine, came to live with us. At 84, although she was beginning to find some parts of her routines challenging, she was able to carry on when we went off to work.

When our son was born the following year, I left my job as project manager for our local electric utility company and became resident manager of our multi-generational living facility. As our son grew older and more independent, we watched his grandmother grow younger, and the balance of care we were providing shifted. I found that my own days were become more and more structured to

meet Katherine's needs, as the boundaries of her world grew smaller when she no longer could take unescorted walks in the neighborhood.

This marked a new stage of caregiving for me. At the urging of our family physician, Katherine began attending the IONA Adult Day Health Center not far from our home. Thankfully, the watchfulness of the day center's staff extended to me as Katherine's caregiver. They answered all my questions (many before I asked them), addressed all my comments, and offered all manner of resources from social workers and nurses to books to read. They also invited me to participate in their first caregivers' support group – an invitation I gladly accepted.

For an hour a week we carers came together in need and talked – sometimes tearfully, sometimes angrily, sometimes overcome with laughter, the only response in our frequently absurd world. We spoke of our fears, our frustrations, our questions, and our accomplishments...and of our loneliness and isolation in the midst of a life that rarely offered a moment alone. Most of all, it was our time, spent in mutual understanding and support, with no interruptions.

I politely declined the offer to meet with a social worker. Over time, however, I began looking at our home with a critical eye, mentally calculating the skid potential of our rugs, trying to visualize what grab-bars would do to our décor! I went to the local home improvement center and was delighted to find a whole section devoted to elder safety – the equipment and aides covered every contingency. Unfortunately, there was no one to advise me on their proper placement and use for a five-foot tall woman who weighed under 100 pounds so I went home empty-handed, my worries in tact.

It was time to call for the social worker. She pointed out that just

because I was a well educated, caring, career woman, it didn't mean that I could or should try to be working at the level of detail I was drawn to – nor should I be trying to both ask and answer the questions. Be the caregiver, she said, ask the questions and let us respond to you. You wouldn't have tried to be your own resource for a technical area at work you didn't know, she admonished me, why on earth try it now. It was then and remains now among the best pieces of advice I have ever been given.

Katherine's days at IONA meant time and energy for me to be wife, mother, homemaker, and caregiver with an ease that would otherwise not have been possible. Katherine's last months were spent surrounded by family, friends, and caregivers. She died at home at age 92, with dignity and love.

Caring for my parents has been very different. While Katherine's last years of life were marked by mostly gentle declines, both my parents were stricken with debilitating injuries and illnesses. First my father fell and required two months of hospitalization and rehabilitation. I managed my parents' home as well as ours, and my mother and I took turns spending days with my father. My husband was the evening visitor and our then nine-year-old son made daily cards to cheer his grandfather and visited him frequently. Three years ago next week, we welcomed my father home for Thanksgiving and began the holiday season knowing that we were making special memories. Exhausted, my parents settled in to a new life, each needing to take most of the day to accomplish the simplest of routines. I too was exhausted, but found that I needed most was the care support that I had found at IONA. I was surrounded by friends who were thoughtful, caring, and willing to help but I was too worn down to organize them to support me. Two months later, just as we all were finding our way more easily, my father was diagnosed with terminal pancreatic cancer. Thirteen days later, he died peacefully at home – constant care and companionship provided by my mother, my husband, my son, me,

and Doris, who had been constantly by Katherine's side at the end of her life.

As we struggled to cope with the swift loss of my father, we realized that my mother, thought to be forgetful and confused due to the stresses of caring for my father, in fact was herself slowing down significantly. Before another six months passed, she became ill and moved in with us. This time, our care was not enough, and following a brief hospital stay, my mother moved to a rehabilitation facility where she could have physical therapy to strengthen her weakened body, and a structure within which she could begin to reestablish her daily routines. In time, her illness receded, her zeal to maintain as much self-determination as possible returned, and she moved to The Methodist Home, a retirement facility just five blocks from us.

I, too, found self-determination to once again be part of my life as I was freed of the urgencies of being a full-time caregiver. With delight, I turned to the joys of being a wife, mother, homemaker, volunteer at church and school, friend, walker and gardener, with newfound flexibility. When I broke my foot in two places because I'd not been a long-distance walker for a while and my body couldn't keep up with my enthusiasm, the consequences weren't overwhelming. I turned to gentler activities and carried on.

Thank you.

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